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Core Indicator Set for Measuring Quality of Care in Necrotising Enterocolitis: A European Delphi Study

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ABSTRACT

Aim: Inconsistent guidelines and practice variations in necrotising enterocolitis (NEC) hamper care improvements. A universally accepted quality indicator set is needed to standardise and improve care throughout Europe. We aimed to establish a core set relevant to NEC patients and experts.

Methods: Clinicians, researchers, and patient representatives evaluated 27 baseline patient characteristics and 41 quality indicators identified by a literature review. Items were rated on a nine-point Likert scale during three online Delphi survey rounds, followed by a consensus meeting.

Results: From 19 European countries, 113 participants completed all Delphi rounds, including five patient representatives. All stakeholders reached consensus on eight baseline characteristics. Among the indicators that reached consensus, five of the top

Abbreviations: ERNICA, European Reference Network for rare Inherited and Congenital (digestive and gastrointestinal) Anomalies; NEC, necrotising enterocolitis; QI, quality indicator.

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10 were mutually prioritised by patients and experts. In the consensus meeting, attended by two patient representatives and 49 experts from 16 countries, four additional indicators were included. The final core set comprised eight baseline characteristics and nine indicators: one healthcare structure, three care process and five outcome indicators.

Conclusion: This study established nine core quality indicators for NEC treatment through consensus among clinicians, researchers, and patient representatives. Their implementation in European clinical audits supports inter-institutional benchmarking, ultimately enhancing care and outcomes for infants with NEC.

1 | Introduction

Necrotising enterocolitis (NEC) affects 2%–7% of very low birth weight preterm infants and is a leading cause of morbidity and mortality, with overall mortality ranging between 20% and 30% [1–5]. Despite years of extensive research and clinical experience, no new treatment options for NEC have been introduced in the last two decades [3]. There are significant variations in outcome reporting in NEC treatment trials, which hampers evidence synthesis and subsequent treatment implementation [6, 7]. Similarly, there is a paucity of internationally supported guidelines, amounting to remarkable practice variations in medical and surgical management of NEC [8, 9]. This underscores the need for care standardisation and optimisation.

Clinical auditing is a proven method to ascertain high quality of care by using quality indicators (QIs) to identify, monitor, and evaluate variations in clinical practice and outcomes on an inter-institutional level [10–12]. A well-balanced core QI set comprising indicators of healthcare structure, care process, and treatment outcomes can identify specific, actionable points for care improvements and future research [10, 13–14]. Applying this benchmarking method to a rare disease such as NEC is most valuable when conducted on an international scale. Hence, a NEC core QI set should be built upon international consensus to ensure clinical relevance and applicability in multiple countries. Within the European Reference Network for rare Inherited and Congenital (digestive and gastrointestinal) Anomalies (ERNICA), which includes NEC, we aimed to establish a multidisciplinary international NEC core QI set. The purpose of this NEC core QI set is to facilitate between-hospital benchmarking of NEC quality of care by using QIs relevant to all stakeholders, including clinicians, researchers, patients and their families. It will serve as the foundation for the NEC Registry in the European Paediatric Surgical Audit, the international quality registry under ERNICA.

2 | Patients and Methods

This project followed the guidelines of the previously published NEC Core Outcome Set protocol, with minor adjustments in the consensus criteria to align with previous and ongoing European Paediatric Surgical Audit and ERNICA QI projects [15, 16]. The involvement of former NEC patients and their parents in this NEC core QI set project was described using the Guidance for Reporting on Involvement of Patients and Public short-form checklist (Appendix S1) [17]. This report was constructed in accordance with the Delphi Studies Recommendations for Interdisciplinary Standardised Reporting (Table S1) and Core Outcome Set STAndards for Reporting [18, 19].

2.1 | Participants

We formed a multidisciplinary international steering group, based on recognised expertise within ERNICA and professional networking, to guide NEC core QI set development. It comprised 16 members from eight European countries, including paediatric surgeons, neonatologists, patient representatives, a paediatric gastroenterologist and a biomedical researcher (Table S2). For the consensus process, we aimed to form three participant stakeholder panels. These included: a patient representative panel including former NEC patients and their parents, a neonatal phase expert panel consisting of clinicians and researchers with expertise on NEC care, and a non-neonatal phase expert panel comprising clinicians and researchers involved in the follow-up care of NEC. We included non-neonatal experts in a separate panel as we hypothesised that they would provide a unique perspective on longer-term indicators.

Patient representative panel participants were approached through multiple patient organisations. The English NEC patient organisation, NEC UK, was involved. General preterm infant organisations of Europe (European Foundation for the Care of Newborn Infants), France (SOS Préma), the Netherlands (Care4Neo), and the United Kingdom (Bliss) were contacted. Additionally, intestinal failure patient organisations of Belgium (Hello Totale Parenterale Nutritie), France (La Vie par un Fil), and the Netherlands (Stichting Darmfalen) were contacted. Participating patient representatives and experts were also allowed to share the invitation with patient representatives within their network.

For the neonatal and non-neonatal expert panels, we firstly approached several experts within the steering group members' network. Next, we requested each ERNICA expert centre to invite at least one neonatologist, paediatric surgeon, and paediatric gastroenterologist to participate. To identify additional NEC experts, also outside the ERNICA network, we conducted a bibliometric SciVal analysis retrieving relevant NEC researchers based on citations and scientific output on NEC [15]. Through this method, we approached another 231 NEC experts from over 20 European countries to participate. After reading the information on the NEC core QI set project and the stakeholder groups, participants were able to select one panel most fitting to their experience.

2.2 | Delphi Preparation

The NEC core QI set was developed using a modified Delphi method [11, 16, 20–22]. After a preparatory phase, the Delphi process consisted of three survey rounds and a consensus meeting.

Summary

- To address practice variations in necrotising enterocolitis, a universally accepted quality indicator set was needed to standardise and improve care throughout Europe.
- This study developed a core set of eight baseline characteristics and nine quality indicators through a Delphi study involving 113 experts and patient representatives from 19 countries.
- The indicators support inter-institutional benchmarking, continuous quality improvement, and research to improve care and outcomes in necrotising enterocolitis.

We conducted a literature search for known indicators in NEC care for the databases MEDLINE and Embase, which yielded no results (Appendix S2). Subsequently, we composed a search strategy for MEDLINE to include all systematic reviews and meta-analyses on NEC over the past 10 years (Appendix S3). The last search was conducted on 18 September 2023. From 413 articles, we extracted maternal and patient characteristics, care structure and process characteristics,fe and outcome measures. NEC outcome measures identified in a previous systematic review were added [7]. All items were included in the indicator long list and categorised by the coordinating group (OCvV, IdHJ, DR, MvdK, JPO, JBFH). Items relevant for contextual interpretation of QIs or for correction of case mix factors were categorised as baseline patient characteristics. QIs were categorised as a structure indicator regarding healthcare structure quality, a process indicator regarding care process quality, or an outcome indicator regarding treatment outcome quality. Preliminary definitions used throughout the Delphi rounds were based on NEC literature [7], with adaptations by the steering group (Appendix S4). We carefully avoided ambiguity of language, and clarifications for scientific terms were provided.

The indicator long list comprised 23 baseline characteristics and 121 structure, process, and outcome indicators. As we aimed for approximately 40 indicators in the Delphi process, we conducted a preliminary survey among the NEC core QI set steering group, using REDCap (Vanderbilt University, Nashville, Tennessee, USA) [23, 24]. Indicators were rated anonymously on a nine-point Likert scale and additional items could be suggested. This was followed by a steering group discussion. The final short list of candidate indicators used in the Delphi process included 27 baseline characteristics and, based on summated ratings, the top 41 indicators (Appendix S4). Indicators related to NEC prevention fell beyond the study scope and were excluded.

2.3 | Delphi Process

For Delphi surveys we used Welphi (Decision Eyes, Lisbon, Portugal). Participants were asked whether an item should be included in the NEC core QI set to enable interpretation of indicators, that is, baseline characteristics, or to compare quality of NEC care between hospitals, regions or countries, that is, quality indicators. All 27 baseline characteristics and 41 indicators were rated on a nine-point Likert scale. On this scale ratings of one through four were labelled totally disagree through mildly disagree, five was labelled neither agree nor disagree, and six through nine were labelled mildly agree through totally agree. Participants were able to post anonymous comments on individual items that were visible to fellow participants in subsequent rounds. At the end of round one, participants were requested to suggest any item they considered important but was not included in the list. Proposed additional items were reviewed by the NEC core QI set steering group and added to the indicator list after round one when proposed by at least two participants or when deemed suitable by the steering group after a vote.

All participants who completed Delphi round one were invited to round two. Participants were presented with their own scores, the median score, the percentage of participants rating an item seven or higher, and comments from round one within their stakeholder panel. After considering the views within their panel, participants were asked to rescore the items. Also, items added after round one were scored for the first time. All participants who completed Delphi round two were invited to round three, where their own ratings and those of all other panels were displayed. We also displayed which items preliminarily reached the consensus in criterium, as defined below, based on round two results. Participants were asked to rescore all round two items, except those that met the consensus out criterium, as defined below. We allowed at least four weeks per Delphi round, sending a maximum of three reminders to minimise attrition.

2.4 | Consensus Definition

For baseline characteristics and indicators included in the NEC core QI set, we defined consensus in as 75% or more of participants rating an item seven through nine with a median rating of eight or more. Consensus out was defined as at least 75% of participants rating an item one through three with a median rating of two or less [16]. Items meeting neither of both definitions were classified as having no consensus.

2.5 | Consensus Meeting

All participants who completed Delphi round three were invited to an online consensus meeting. Attendees were presented with the baseline characteristics reaching consensus among all three panels, and the top 10 indicators. QIs were ranked by median score and percentage of votes of seven or more, presenting the top 10—in either the patient representative group or the combined expert group which included the neonatal and non-neonatal expert panels. This approach aimed to ensure a balanced representation of patient representatives and experts while limiting NEC core QI set size for applicability. Only the top 10 indicators that did not reach consensus in both the patient representative and combined expert group were discussed in the consensus meeting. A supplementary file containing all relevant items, their preliminary definitions, and all comments

from the three Delphi rounds was provided to attendees in advance of the meeting.

Each indicator discussion started with the round three results per group and a patient representative introducing the indicator by sharing their views on its importance. In a moderated discussion, attendees were encouraged to critically evaluate if the indicator is relevant, measurable, and specific to be improved by adapting NEC care. QIs that did not make the top 10 were discussed only after a unanimous decision by all attendees. After each moderated discussion, indicators were rescored anonymously once again on a nine-point Likert scale. Indicators reaching consensus were added to the NEC core QI set.

2.6 | Post-Consensus Definition Meeting

Preliminary baseline characteristic and QI definitions used throughout the Delphi rounds were based on NEC literature, identified through our previous literature review or systematic review [7], with adaptations by the steering group. The final definitions were formulated after considering all participant feedback throughout the surveys and consensus meeting. In a post-consensus definition meeting, the steering group discussed and unanimously agreed on definitions of all items included in the NEC core QI set.

2.7 | Statistical Analyses

We compared mean scores of the patient representative group and combined expert group, and scores of the various clinical specialties. Potential attrition bias was assessed by comparing mean scores—combined per participant for all items—of those who completed all three Delphi rounds with those who did not. We performed Mann–Whitney *U* tests using SPSS Windows version 28.0 (IBM Corp, New York, USA). Two-tailed significance level was set at $p < 0.05$.

2.8 | Informed Consent

Due to the nature of this survey study, it was not subject to the Dutch Medical Research Involving Human Subjects Act. Ethical approval was waived by the Institutional Review Board of the University Medical Center Groningen. Participants registered voluntarily after being informed about the nature of the study, and electronic informed consent was obtained prior to each Delphi survey round. Withdrawal was allowed at any time.

3 | Results

3.1 | Delphi Round One

A total of 142 people registered for the initial Delphi survey round. The round was completed by 123 participants (Table 1). Preliminary consensus was reached in all three panels for six baseline characteristics and 10 indicators (Appendix S5). Participants suggested 29 additional items, including three baseline characteristics and 26 indicators. Among these, 10 items were suggested by at least two participants and therefore added to the candidate item list in round two (Appendix S6). The remaining items were voted on anonymously in a steering group meeting, including a patient representative, using a nine-point Likert scale. None reached consensus for inclusion in round two.

3.2 | Delphi Round Two

Including added items, 29 baseline characteristics and 49 indicators were rated. Of the initial 123 participants, 115 (93%) completed the second survey (Table 1). After round two, eight baseline characteristics and 23 indicators preliminarily reached consensus in all panels (Appendix S5). No items met the consensus criteria for elimination.

3.3 | Delphi Round Three

As no items were dropped in round two, the same candidate-item list was used. Of the initial 123 participants, 113 (92%) completed round three, representing all stakeholders (Table 1). Participants from 19 European countries contributed, and the slight majority was male (55%). Experts had a median [interquartile range] of 20 [12-25] years of experience with NEC treatment and/or research and saw 10 [7-15] NEC cases per year. The patient representative group included individuals from the Netherlands, Norway and the United Kingdom; all were female.

The full score list can be found in Appendix S5. Eight baseline characteristics reached consensus in all stakeholder panels. Of the 37 QIs that reached consensus in the patient representative group, indicators number 10 and 11 had the same score. Therefore, the top 11 indicators from the patient representative group were tabled. Of 37 consensus indicators in the combined expert group, the top 10 were tabled. Upon comparison, five indicators within the top 10/11 overlapped between the patient representative and combined expert groups and were directly included in the NEC core QI set (Table 2).

3.4 | Consensus Meeting

Initially, 11 QIs were eligible for discussion and rescoring in the consensus meeting (Figure 1). During the meeting, unanimous agreement was reached to discuss an additional indicator that did not reach consensus in round three: the percentage of NEC survivors with intestinal complaints 2 years after diagnosis.

The consensus meeting was attended by 51 participants from 16 European countries. All three stakeholder panels, which include the neonatal phase expert panel, the non-neonatal phase expert panel and the patient representative panel, were represented during the meeting (Table 1). Of the 11 discussed indicators, four reached consensus after a final vote and were added to the NEC core QI set. For outcome indicator mortality, it was unanimously decided that the distinction between early and late mortality would be disregarded to record the age at death instead.

TABLE 1 | Participants contributing to the necrotising enterocolitis core quality indicator set.

	First Delphi round (% of total)	Second Delphi round (% of total)	Third Delphi round (% of total)	Consensus meeting (% of total)
Patient Representative Panel	6 (5)	5 (4)	5 (4)	2 (4)
Parent of NEC patient	5	4	4	2
Former NEC patient	1	1	1	0
Neonatal Phase Expert Panel	105 (85)	98 (85)	96 (85)	46 (90)
Neonatologist	49	43	42	18
Paediatric surgeon	45	45	45	25
Researcher	7	6	6	2
Nurse	4	4	3	1
Non-Neonatal Phase Expert Panel	12 (10)	12 (10)	12 (11)	3 (6)
Paediatric gastroenterologist	8	8	8	1
Paediatric surgeon	1	1	1	1
Paediatrician	1	1	1	1
Neuropsychologist	1	1	1	0
Researcher	1	1	1	0
Total	123	115	113	51
Represented countries	20 Austria Belgium Denmark Estonia Finland France Germany Greece Ireland Italy Latvia the Netherlands Norway Poland Serbia Slovakia Spain Sweden Switzerland UK	19 Austria Belgium Denmark Estonia Finland France Germany Greece — Italy Latvia the Netherlands Norway Poland Serbia Slovakia Spain Sweden Switzerland UK	19 Austria Belgium Denmark Estonia Finland France Germany Greece — Italy Latvia the Netherlands Norway Poland Serbia Slovakia Spain Sweden Switzerland UK	16 — Belgium Denmark Estonia — France Germany Greece — Italy Latvia the Netherlands Norway Poland Serbia — Spain Sweden Switzerland UK

3.5 | A Core QI Set for NEC Treatment

The NEC core QI set comprises QIs of all three categories: one structure indicator, three process indicators and five outcome indicators. Eight baseline characteristics in this NEC core QI set allow contextual interpretation of indicators and case mix correction. The final items, with their recommended definitions, time points and applications, are summarised in Tables 3–5 and Appendix S7.

3.6 | Bias and Stakeholder Analysis

The Attrition rate was 8% in this Delphi study, with the distribution of participants per panel remaining similar (Table 1). Mean scores did not differ significantly between those who completed all three rounds or not (mean rank 62 vs. 63, $p = 0.963$). This also held true when comparing specifically within the neonatal expert (mean rank 53 vs. 53, $p = 0.963$) and patient representative panel (mean rank 3 vs. 4, $p = 0.770$). In round three, mean scores

TABLE 2 | Quality indicator top 10, based on percentage of votes ≥ 7, for the patient representative group and combined expert group.

Patient representative group ($n = 5$)			Combined expert group ($n = 113$)		
Median rating	**% voted ≥ 7**	**Quality indicator**		**% voted ≥ 7**	**Median rating**
9	100	**Surgical intervention for NEC (*n*, %)**	Late mortality (%)	99.1	9
9	100	**Structured neurodevelopmental follow-up (%, Y/N)**	Early mortality (%)	98.1	9
9	100	Abdominal X-ray for NEC diagnosis (Y/N)	**Surgical intervention for NEC (*n*, %)**	96.3	9
9	100	Shared decision making involving parents (Y/N)	**Short bowel syndrome (%)**	96.3	9
9	100	Cerebral injury on ultrasound after NEC (%)	Type of surgical procedure for NEC (%)	94.4	9
9	100	Intestinal perforation (%)	**Structured neurodevelopmental follow-up (%, Y/N)**	93.5	9
9	100	**Need for reoperation (%)**	Human milk administration (Y/N, %)	93.5	9
9	100	**Neurodevelopmental impairment (%, median score)**	Reinitiation of enteral feeding after NEC (median days)	93.5	9
9	100	Quality of Life (median score)	**Need for reoperation (%)**	93.5	9
9	80[a]	Indication for surgery (%)	**Neurodevelopmental impairment (%, median score)**	93.5	9
9	80[a]	**Short bowel syndrome (%)**			

Note: Overlapping top 10 quality indicators between the stakeholder groups are written in bold. These were directly included in the NEC core QI set, without discussion or rescoring in the consensus meeting. Indicator type is marked by colour shading: structure indicator = orange; care process indicator = blue; outcome indicator = green.
Abbreviation: Y/N, Yes/No.
[a]Rank #10 and #11 in the patient representative group had the same scores and, as no distinction could be made, both were tabled.

between the combined expert and patient representative group did not differ significantly (mean rank 57 vs. 51, $p = 0.686$). Among experts, round three mean scores did not differ significantly between neonatologists and paediatric surgeons (mean rank 45 vs. 43, $p = 0.845$).

4 | Discussion

This NEC core QI set includes nine QIs for healthcare structure, care process, and treatment outcome, recommended for inter-institutional benchmarking of NEC treatment. Additionally, eight baseline characteristics for interpretation and case mix correction of QIs are recommended. This consensus-based core QI set was established by 113 relevant stakeholders in NEC treatment from 19 European countries. We actively involved the patient and parental perspective in addition to the expert opinion. Implementation of this NEC core QI set may help to evaluate and improve the quality of NEC care and to focus research efforts.

Core outcome sets have been developed for multiple paediatric conditions over the last 20 years, including for NEC [27, 33]. Core QI sets are less known and distinguish themselves from core outcome sets by examining not only outcome measures, but also aspects of healthcare structure and care process [10, 11, 16]. Moreover, the goal of core outcome sets is typically to improve future research outcome reporting, whereas a core QI set focuses on evaluating and improving quality of care [14, 16]. Despite having separate aims and processes, most NEC core outcomes also made it into the NEC core QI set in our study. Only quality of life was part of the NEC core outcome set but was excluded in the consensus meeting of our NEC core QI set, as it was not deemed sufficiently measurable and actionable for improvement. Nevertheless, our findings echo the importance of these core outcomes, both in research and quality of care.

Of the nine core QIs, one process indicator and three outcome indicators are aimed at long-term quality of care regarding neurodevelopment and bowel function. This may be a reflection of including non-neonatal experts and giving patient representatives a significant role in the Delphi process. In recent years, long-term consequences of NEC have garnered more attention. A 2022 qualitative study emphasised the long-term

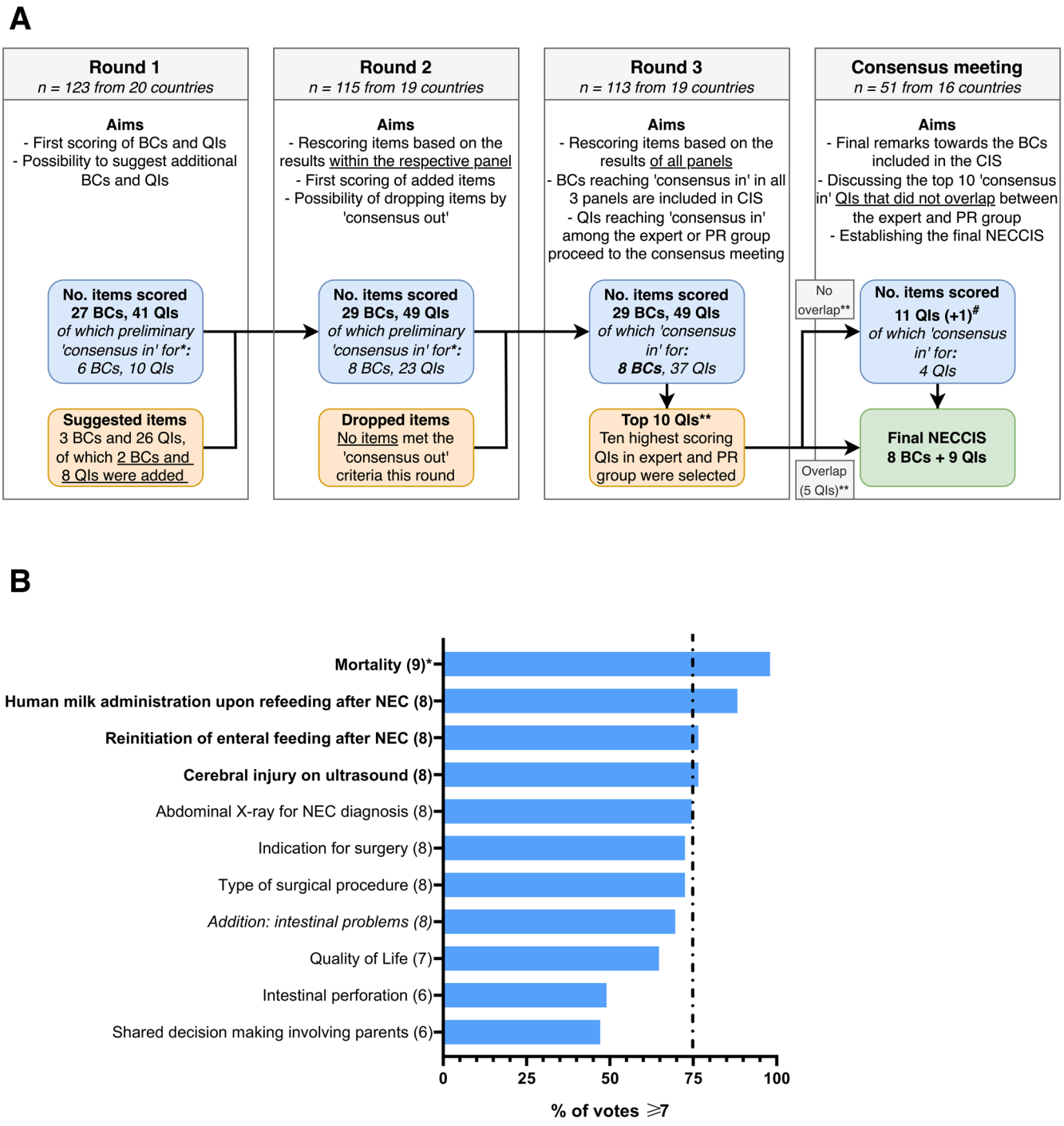

FIGURE 1 | (A) Flowchart displaying the aims and results of each Delphi round. BCs, baseline characteristics; CIS, core quality indicator set; NEC, necrotising enterocolitis; PR, patient representatives; QIs, quality indicators. *Items that preliminarily reached consensus in round one and/or round two were not preliminarily eliminated/selected and were rescored in the subsequent round together with other items. **Because many indicators reached consensus in round three, it was decided that only the top 10 Indicators of the combined (neonatal and non-neonatal) expert group and the top 10 indicators of the patient representative group would be tabled for the consensus meeting; in the patient representative group indicator number 10 and 11 had the same scores, leading to a total of 21 candidate indicators of which 5 overlapped between the expert and patient representative group, leaving 11 indicators for the consensus meeting. #One additional item (*intestinal problems*) was discussed and scored after unanimous decision during the consensus meeting. (B) Final scores collected during the consensus meeting. Quality indicators were rated on a one through nine scale by $n = 51$ attendees. The median rating of an indicator is displayed in parentheses. Consensus was defined as a median indicator rating of 8 or more, with 75% or more of participants rating it 7 or more (dotted line).

TABLE 3 | Necrotising Enterocolitis Core Quality Indicator Set with recommended definitions and time points.

Indicator type	Quality indicator	Recommended indicator measures	Time points
Structure	Surgical intervention for NEC Every operative intervention performed by a paediatric surgeon for NEC management, ranging from percutaneous peritoneal drainage to laparotomy with or without bowel resection	(1) Number of patients with NEC who underwent a surgical intervention at the institution (2) Percentage of NEC patients who had peritoneal drainage for NEC (3) Percentage of NEC patients who had a laparotomy for NEC	Per year
Process	Structured neurodevelopmental follow-up Presence of a protocol or agreement for structural follow-up of infants that survived NEC, including at least two follow-up appointments at standardised time points after NICU discharge, where validated tests for the measurement of neurodevelopment are applied. The validated tests include at least the following domains: motor, cognitive, sensory (hearing and vision) and developmental (neurobehavioral, language or educational). This follow-up may occur in the same institution or in a connected institution	(1) Percentage of (medical and surgical) NEC survivors receiving structured long-term follow-up of neurodevelopment (2) Neurodevelopment is monitored with appropriate and validated scales (Y/N)	Per year
	Reinitiation of enteral feeding after NEC The day of first enteral feeding and the day of reaching full enteral feeding (≥150 mL/kg/day sustained for 24 h) after nil per mouth management of an episode of NEC	(1) Median day of reinitiation of enteral feeding, including trophic feeds, after nil per mouth upon NEC diagnosis in NEC patients (2) Median day of reaching full enteral feeding after nil per mouth upon NEC diagnosis in NEC patients	After NEC diagnosis
	Human milk administration upon refeeding after NEC Human mother's own milk or donor milk is administered in a protocolised fashion to infants that are restarted on enteral feeding after an episode of NEC with the goal to improve gut recovery	(1) There is a protocol for human (donor) milk administration upon refeeding after NEC (Y/N) (2) Percentage of NEC patients started on enteral human mother's own milk vs. human donor milk versus artificial formula versus a combination (specify components and more or less than 50% human) upon refeeding after NEC	After NEC diagnosis
Outcome	Cerebral injury on ultrasound Cerebral injury, including IVH (Papile grade I-IV) [25] and PVL (grade I-IV) [26], diagnosed on neonatal cerebral ultrasound by a trained medical specialist	(1) Percentage of NEC patients with cerebral injury (IVH and/or PVL) on cerebral ultrasound prior to NEC diagnosis (2) Percentage of NEC patients suffering from new or worsening cerebral injury (≥1 grade IVH and/or PVL increase) on ultrasound after NEC diagnosis	Before NEC: ≥24 h before NEC diagnosis. After NEC: ≥2 weeks after NEC diagnosis or surgery (whichever is later).

(Continues)

TABLE 3 | (Continued)

Indicator type	Quality indicator	Recommended indicator measures	Time points
	Need for reoperation Every unplanned reoperation attributable to NEC or its health sequelae performed by a surgeon in patients who had NEC surgery, excluding: planned laparotomy after a bridging drain, planned second-look procedure or ostomy closure	(1) Percentage of surgically treated NEC patients requiring an unplanned NEC-related abdominal reoperation (excluding planned laparotomy after a bridging drain, planned second-look procedure or ostomy closure) (2) Percentage of surgically treated NEC patients requiring an unplanned NEC-related non-abdominal reoperation (e.g., central line placement)	24 h up to 2 years after the surgical intervention for NEC (date recorded)
	Short bowel syndrome-associated intestinal failure (SBS-IF) • SBS: A critical reduction of functional gut mass, secondary to bowel resection, below the minimum necessary for adequate digestion and absorption of macronutrients and/or water and electrolytes for adequate growth and development in children [27–30] • IF: Intravenous supplementation (parenteral nutrition) is required to maintain health and growth for a minimum of 60 days within a 74 consecutive day interval [28–30]	Percentage of surgical NEC survivors with bowel resection suffering from SBS-IF, defined as parenteral nutrition for ≥ 60 days within a 74 consecutive day interval from the start of nil per mouth management upon NEC diagnosis	In the first year of life [27]
	Neurodevelopmental impairment Significant deviation or loss of neurodevelopmental function (motor, cognitive, sensory and developmental) resulting in below average performance, according to the standards of the applied validated test, on at least one of the following domains: motor, cognitive, sensory (hearing and vision) and/or developmental (neurobehavioral, language or educational) issues [27, 31]	(1) Percentage of NEC survivors having neurodevelopmental impairment based on the standards of applied validated tests (2) Percentage of NEC survivors diagnosed by a medical specialist with: hearing loss, vision loss or cerebral palsy (3) Median school performance score based on an age-appropriate and validated test	At the corrected age of 18–24 months and/or at school age [27]
	Mortality • All-cause mortality • NEC-related mortality: Mortality as consequent upon NEC or a complication of NEC treatment, if possible, with confirmation of NEC diagnosis using either pathology or histology [27]	(1) Percentage of all-cause mortality among NEC patients (age at death recorded) (2) Percentage of NEC-related mortality among NEC patients (age at death recorded)	Per year

Abbreviations: IF, intestinal failure; IVH, intraventricular haemorrhage; NEC, necrotising enterocolitis; NICU, neonatal intensive care unit; PVL, periventricular leukomalacia; SBS, short bowel syndrome; Y/N, Yes/No.

TABLE 4 | Baseline patient characteristics for interpretation and case mix correction in quality indicator assessment.

Baseline patient characteristic	Recommended definition
Birth weight	Birth weight in grams
Relation BW/GA	(1) Small for gestational age (Y/N): birth weight < 10th percentile for the corresponding gestational age according to national standard growth charts (2) Intrauterine/fetal growth restriction (FGR) (Y/N): in accordance with the international consensus definition of Gordijn et al. [32] *Early FGR* (*< 32 weeks*) *solitary parameters*: abdominal circumference (AC) < 3rd centile, estimated fetal weight (EFW) < 3rd centile and absent end-diastolic flow in the umbilical artery (UA); four contributory parameters: AC or EFW < 10th centile combined with a pulsatility index (PI) > 95th centile in either the UA or uterine artery *Late FGR* (*≥ 32 weeks*) *solitary parameters*: AC or EFW < 3rd centile; contributory parameters (EFW or AC < 10th centile, AC or EFW crossing centiles by > two quartiles on growth charts and cerebroplacental ratio < 5th centile or UA-PI > 95th centile)
Type of feeding	(1) Age (in days) at first feed (2) Age (in days) at full enteral feeds, full enteral feeds defined as ≥ 150 mL/kg/day sustained for 24 h (3) Specify all types of oral feeding that the newborn received prior to NEC diagnosis: no oral intake, mother's own milk, human donor milk, fortified mother's own milk, fortified human donor milk, artificial formula, hydrolysed protein formula (4) Specify all types of oral feeding that the newborn received in the 24 h prior to NEC diagnosis: no oral intake, mother's own milk, human donor milk, fortified mother's own milk, fortified human donor milk, artificial formula, hydrolysed protein formula. If applicable, specify fortifier: whole protein or hydrolysed formula and cow's or human milk-derived fortifier[a]
Cardiovascular condition	Is there a hemodynamically significant vascular or cardiac malformation, excluding persistent ductus arteriosus and open foramen ovale? (Y/N and specify)
PDA treatment	(1) PDA that required treatment (yes/no/unknown)? Date of diagnosis (if applicable)[b] (2) Management of the PDA: no treatment, medical treatment (specify: acetaminophen; ibuprofen; high dose ibuprofen; indomethacin) or surgical treatment (specify: cardiac catheterization or surgical ligation/clipping)? Date of treatment (if applicable)?
Maximum NEC Stage	(1) Maximum modified Bell's stage (1A-3B) (2) Specify the presence of disease signs *Systemic*: temperature instability, apnea, bradycardia, metabolic acidosis, thrombocytopenia, neutropenia, disseminated intravascular coagulation, hypotension (requiring fluid, vasopressor or inotropic support) *Abdominal*: gastric retention, bilious aspirates, faecal blood, abdominal distension, abdominal tenderness, abdominal cellulitis, signs of peritonitis *Radiographic (X-ray or ultrasound)*: intestinal dilation, ileus, pneumatosis intestinalis, ascites, portal venous gas, pneumoperitoneum
Weight at NEC diagnosis	Weight at NEC diagnosis in grams[a]
Time to surgery	Hours spent from the diagnosis of NEC until the time at which surgery starts (knife to skin) or a peritoneal drain is inserted

Abbreviations: NEC, necrotising enterocolitis; PDA, patent ductus arteriosus; Y/N, Yes/No.
[a]The moment of NEC diagnosis is defined as the moment of the X-ray that is diagnostic for NEC (pneumatosis intestinalis, portal venous gas and/or pneumoperitoneum) with a concurrent clinical picture of NEC (e.g., bilious gastric aspirates, faecal blood, abdominal distension and/or clinical deterioration).
[b]There is no international consensus on the definition of a hemodynamically significant patent ductus arteriosus (PDA). Hence, we practically recommended registering only treated PDAs as baseline characteristic.

impact on family and patients [34]. We improved upon shortcomings in some previous paediatric Delphi studies by harnessing patient representatives' experiences to improve NEC care [33, 35–36].

Although in its early stages, clinical auditing in rare paediatric conditions is gaining ground, for instance through the recent oesophageal atresia core QI set [16]. Comparatively, our NEC core QIs are less surgery-specific, reflecting the broad spectrum

TABLE 5 | Potential application of the NEC core QI set in inter-institutional benchmarking and improvement of NEC quality of care.

Indicator type	Quality indicator	Potential role in NEC quality-of-care benchmarking between institutions, regions and countries
Structure	Surgical intervention for NEC	Inter-institutional comparison: Yearly number of surgical interventions for NEC (distinguishing laparotomy and peritoneal drainage), combined with outcome indicators
		Quality goals: (1) identifying a minimum number of yearly surgeries required per center for an acceptable complication rate; (2) identifying whether a predominance of laparotomy or peritoneal drainage negatively affects outcome indicators
Process	Structured neurodevelopmental follow-up	Inter-institutional comparison: Yearly percentage of NEC survivors receiving structured neurodevelopmental follow-up with validated scales
		Quality goals: Maximising the percentage of NEC survivors receiving structured neurodevelopmental follow-up per center to optimise long-term care and research for NEC patients
	Reinitiation of enteral feeding after NEC	Inter-institutional comparison: Median day of reinitiation of enteral feeding and median day of reaching full enteral feeding after nil per mouth management for an episode of NEC, combined with outcome indicators
		Quality goals: Identify, by comparing different centers, whether shorter or longer times to (full) enteral feeding after a NEC episode have a positive effect on gut recovery
	Human milk administration upon refeeding after NEC	Inter-institutional comparison: Percentage of NEC patients receiving human milk vs. formula upon refeeding after an episode of NEC, combined with outcome indicators
		Quality goals: Identifying, by comparing different centers, whether human milk administration for refeeding after NEC improves gut recovery
Outcome	Cerebral injury on ultrasound	Inter-institutional comparison: Percentage of NEC patients suffering from new or worsening cerebral injury on ultrasound after NEC diagnosis, combined with other indicators and baseline characteristics
		Quality goals: (1) Minimising the percentage of NEC patients per center suffering from new or worsening cerebral injury during a NEC episode; (2) Prompting further research into causes of cerebral injury by identifying unique institutional factors based on the core QI set and beyond
	Need for reoperation	Inter-institutional comparison: Percentage of surgically treated NEC patients requiring an unplanned reoperation, combined with other indicators and baseline characteristics
		Quality goals: (1) Minimising the percentage of NEC patients per center requiring an unplanned reoperation; (2) Prompting further research into causes of unplanned reoperation by identifying unique institutional factors based on the core QI set and beyond
	Short bowel syndrome-associated intestinal failure (SBS-IF)	Inter-institutional comparison: Percentage of surgical NEC survivors with bowel resection suffering from SBS-IF, combined with other indicators and baseline characteristics
		Quality goals: (1) Minimising the percentage of surgical NEC patients per center suffering from SBS-IF; (2) Prompting further research into causes of SBS-IF by identifying unique institutional factors based on the core QI set and beyond
	Neurodevelopmental impairment	Inter-institutional comparison: Percentage of NEC survivors having neurodevelopmental impairment at the corrected age of 18–24 months or older, combined with other indicators and baseline characteristics and while adjusting for the number of survivors receiving follow-up (process indicator)
		Quality goals: (1) Minimising the percentage of NEC survivors per center with neurodevelopmental impairment; (2) Prompting further research into causes of neurodevelopmental impairment by identifying unique institutional factors based on the core QI set and beyond – thereby optimising long-term care and research for NEC patients

(Continues)

TABLE 5 | (Continued)

Indicator type	Quality indicator	Potential role in NEC quality-of-care benchmarking between institutions, regions and countries
	Mortality	Inter-institutional comparison: Yearly percentage of all-cause and NEC-related mortality among NEC patients, combined with other indicators and baseline characteristics Quality goals: (1) Minimising the mortality rate of NEC patients; (2) Prompting further research into causes of death by identifying unique institutional factors based on the core QI set and beyond

Abbreviations: NEC, necrotising enterocolitis, SBS-IF, short bowel syndrome-associated intestinal failure; QI, quality indicator.

of the disease course of NEC. We also had lower attrition and involved more stakeholders and countries, potentially demonstrating a growing interest in clinical benchmarking. These differences highlight that quality of care is disease-specific and that the need for benchmarking may be even more pressing in highly lethal conditions such as NEC.

5 | Strengths and Limitations

We established the first NEC core QI set, further paving the way for collaborative, international expert-driven best practices in rare paediatric conditions. The participation of a large and diverse group of stakeholders strengthens the international applicability and comprehensiveness of our core QI set. Once indicators proposed in our study are benchmarked to optimise care to the best available evidence and practices, these core QIs and other described QIs can identify overarching shortcomings and direct future NEC research.

Despite approaching multiple patient organisations, patient representative participation was markedly less than aimed for. This issue was also encountered in other core outcome set and core QI set efforts [16, 27, 28, 37]. This was possibly exacerbated by the inherent complexity of care quality. Although recruiting and retaining lay participants remains challenging, we attempted to increase their impact in the study. We weighed patient representatives' scores equal to the experts' in top 10 QI selection and assigned speaker moments during the consensus meeting. We also noted limited involvement of non-neonatal experts, prompting us to merge expert panels for the final QI selection. This could result from the fact that many neonatal experts also tend to be involved in the follow-up phase in different degrees. Finally, gestational age at birth was a baseline characteristic that reached consensus in only two of the three panels, but we strongly recommend including it when setting up a NEC registry.

6 | Conclusion

We developed a comprehensive NEC core QI set consisting of eight baseline characteristics and one structure, three process and five outcome indicators. This core set was established through a thorough international Delphi process involving both NEC experts and patient representatives. The selected indicators enable evaluation and benchmarking of core quality of care aspects in NEC treatment, to improve future NEC care and focus research efforts. This NEC core QI set will be implemented in the European Paediatric Surgical Audit and ERNICA NEC Registry and facilitate recognition of best practices in NEC care, thereby potentially prompting care improvements internationally.

Author Contributions

Dr. Van Varsseveld conceptualised and designed the study, designed the data collection instruments, collected data, conducted the initial analyses, drafted the initial manuscript, and critically reviewed and revised the manuscript; Drs Boukhris, Duci, Duess, Kooi, Matthyssens, Mesas Burgos, Miserez, Norsa, Palleri, Sfeir, Vermeulen, Profs Eaton and Lacher and Ms. Spruce conceptualised and designed the study, supervised data collection, and critically reviewed and revised the manuscript for important intellectual content; Prof Hulscher and Drs Prat Ortells, De Haro Jorge, Rossi and Van der Kamp conceptualised and designed the study, coordinated and supervised data collection, and critically reviewed and revised the manuscript for important intellectual content. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Deidentified individual participant data (including data dictionaries) will be made available, in addition to study protocols, the statistical analysis plan, and the informed consent form. The data will be made available upon publication to researchers who provide a methodologically sound proposal for use in achieving the goals of the approved proposal. Proposals should be submitted to o.c.van.varsseveld@umcg.nl.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Appendix S1.** Guidance for Reporting on Involvement of Patients and Public (GRIPP2) short-form checklist. **Appendix S2.** Initial search strategy for literature on quality indicators in NEC care. **Appendix S3.** MEDLINE search strategy for a literature review to extract baseline characteristics and quality indicators for NEC care for the indicator long list. **Appendix S4.** Preparatory survey and item short list (SL) with preliminary definitions. **Appendix S5.** All Delphi round scores per panel. **Appendix S6.** Suggested additional items after Delphi round one; scores and definitions. **Appendix S7.** Final NEC core quality indicator set including scores and definitions after the post-consensus meeting. **Table S1.** EQUATOR checklist: Delphi studies in social and health sciences – recommendations for an interdisciplinary standardized reporting (DELPHISTAR). **Table S2.** Necrotising Enterocolitis Core Quality Indicator Set steering group.